Alternative Solutions

What Role Should "Informal Caregivers" Play in Alternative LTC Solutions?

Session #33
Tuesday March 15, 2016
10:45 am – 12:00 pm



Session Speakers



- Don Redfoot, Ph.D., Independent Consultant, Formerly with AARP Public Policy Institute
- Howard Gleckman, Resident Fellow, Urban Institute
- Kathy Kenyon, J.D., Family Caregiver, Independent Consultant

Nothing "Informal" About Caregiving!



- The panel was unanimous and emphatic in their opinion that the term "informal caregiver" should be eliminated from the lexicon of LTSS terms
- Caregivers shoulder a wide range of tasks that are very specific, often technically and physically difficult, and at great cost
- Caregivers often take on very formal and legal responsibilities for decision-making

Never Before in History...



- Have so many older people reached such advanced old age
- Has disability lasted so long, exhausting resources and requiring caregiving even into the retirement years of caregivers
- Have so many caregivers, especially women, been required to balance so many work and family responsibilities
- Have caregivers been called upon to provide such complicated health and decision-making services

Caregiving Implications of an Aging Society



- Those born in 1900 only 41% lived to 65
- Those born in 2010 84% will live to 65
- Life Expectancy at 65 has increased by 5 years for men and more than 3 years for women over the past 50 years
- Those who reach 65 >70% will have some LTSS need; 52% HIPAA level
- Average duration, 2 years; 3.9 years among those with any LTSS need

Higher Care Needs – Fewer Resources



Probability of 5+ Years HIPAA needs, 65+

- By Income
 - Lowest Income Quintile: 18.9%
 - Highest Income Quintile: 10.1%
- By Marital Status
 - Unmarried: 16.1%
 - Married: 12.8%
- By Gender:
 - Women: 17.8%
 - Men: 9.8%

Tasks Provided by Caregivers



- 59% perform at least one ADL assistance task
- On average, 4.2 of 7 IADL tasks
- 57% perform medical/nursing tasks
- Just 14% of those performing medical/nursing tasks report receiving some training or preparation
- 40% of caregivers report a "high burden"
- One in 3 report no help paid or unpaid

The Average Caregiver



- Female: 60%
- 49 years old (one in ten 75+)
- Spends 24.4 hours a week giving care (a quarter 41 or more hours)
- Has been giving care for 4 years (a quarter for more than 5 years)
- Female Caregivers are older and provide more hours of care

Caregiver Ratios Over Time



- 1990—2010: Boomers aged into prime caregiving years. Caregiver ratio high and increased from 6.6 to 7.2
- 2010—2030: As boomers progress into old age, the caregiver ratio will decline sharply from 7.2 to 4.1. Oldest boomers begin to reach age 80 in the mid-2020s
- 2030—2050: All boomers will become 80+. Caregiver ratio will drift downward from 4.1 to 2.9

More Women Employed



- 1963, year of the last episode of "Leave It To Beaver": 39% of women in paid labor force
- Today, 57% of women are employed
- 60% of caregivers are employed
- 20% of female workers & 16% of male workers are also family caregivers – up from 13% of all caregivers in 1999

Caregiving: The Value and the Costs



- 2013 Valued at \$470 Billion; Total
 Medicaid expenditures were \$449 Billion
- One in 5 retirees left their jobs early to provide care to family member
- Average lifetime cost to caregivers who leave the workforce – \$303,880
- Cost to employers in lost productivity –
 \$28 Billion

Managing the Risks to Caregivers



- In short, the costs and risks of caregiving are increasing as:
 - The number of those needing assistance increases
 - The duration and intensity of the needs increase
 - The direct and opportunity costs increase for those managing work and care while preparing for their own retirement
- How will we manage those costs and risks?

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What Role Should "Informal Caregivers" Play in Alternative LTC Solutions?

Howard Gleckman
Urban Institute



What role should family caregivers play?



- The role they always have:
 - As the key support for their loved ones
- But they can't do it alone
 - Enormous physical, financial, and emotional cost
 - Increased need for technical skills
 - Outside help does not reduce family care, but it does change it

What Do Family Caregivers Need?



Support

- Where do I get help? Information services
- Small things matter most: rides, meals, friendly visits

Training

- Need for technical skills grows, yet few opportunities to learn
- Role of insurers/health systems

Community

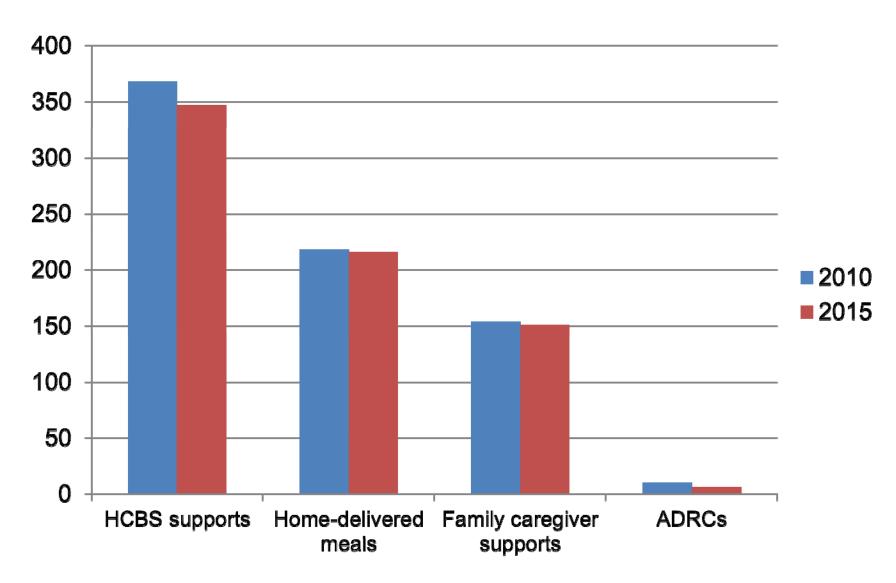
- Senior villages
- Faith communities

Respite

- Adult Day Care
- Volunteers

Will Government Help?

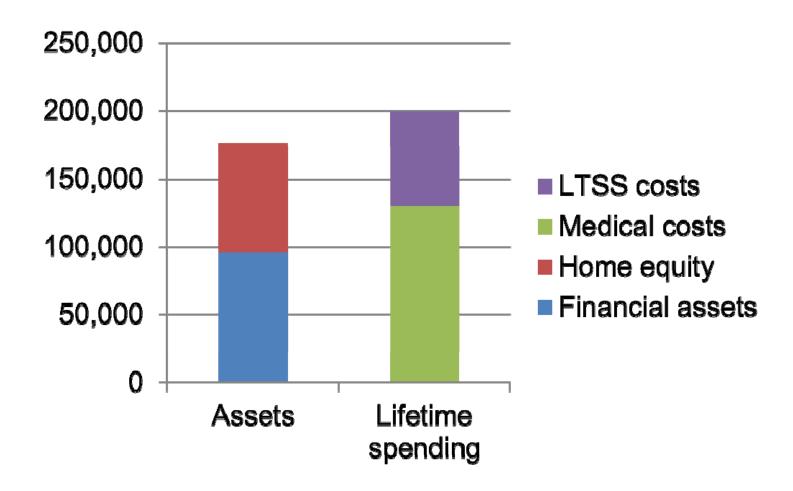




How about personal savings?



Assets at age 65 vs. future lifetime costs

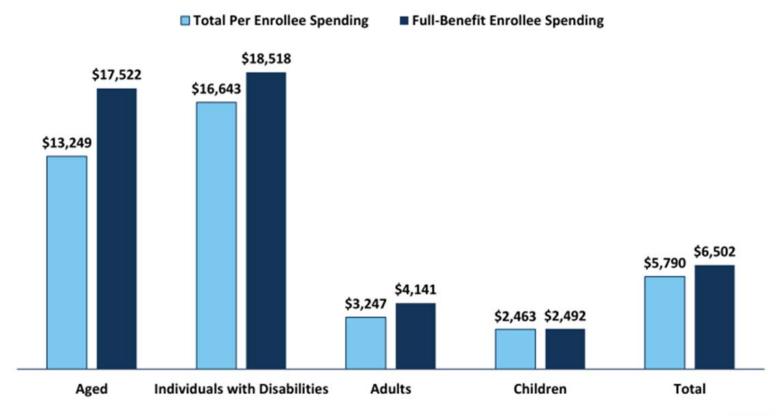


Or Medicaid?



Figure 1

Per enrollee spending – total vs. full-benefit enrollees, FY 2011



SOURCE: Kaiser Commission on Medicaid and the Uninsured and Urban Institute estimates based on data from FY 2011 MSIS and CMS-64 reports. Because 2011 MSIS data were unavailable, 2010 MSIS & CMS-64 data were used for FL, KS, ME, MD, MT, NM, NJ, OK, TX, and UT.



Where Will The Money Come From?



LTCi

- Reimbursement in an age of choice?
- Catastrophic cash benefit
- What about pre-HIPAA caregiver support?
- Managed Care
 - Duals Demonstrations
 - Medicare Advantage
 - Will the numbers work?
 - Person-centerdness v. evidence-based

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Thank you

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